UNITED STATES DISTRICT COURT	
NORTHERN DISTRICT OF NEW YORK	ζ

CHARLES BRYANT, individually and as next friend and guardian of D.B., et al.,

Plaintiffs,

v.

No. 8:10-CV-36 (GLS / RFT)

NEW YORK STATE EDUCATION DEPARTMENT, et al.,

Defendants.

## **DECLARATION OF CARMEN PENA**

- I, Carmen Pena, upon my own personal knowledge, hereby depose and declare the following:
  - 1. I am the mother and a legal guardian of G.T.
- 2. G.T. is a 15 year-old boy from New York who suffers from Autism, Mental Retardation, and a severe behavior disorder that causes him to engage in dangerous and disruptive behaviors.
- 3. G.T. is currently receiving behavior modification treatment and special education at the Judge Rotenberg Educational Center, Inc. ("JRC"), in Canton, Massachusetts.
- 4. G.T. has a long history of engaging in aggressive, destructive, disruptive, noncompliant and self-injurious behavior, including: unpredictable physically aggressive behavior; screaming and yelling; disrobing at inappropriate times and in inappropriate places; foot stomping; masturbating at inappropriate times and touching his genitals through his clothing; severe head-banging and other self-injurious behaviors; destruction of cabinets, doors, windows, beds, carpets, walls, furniture, televisions, computers, and appliances at school and at

my home; denting a refrigerator by head-banging; attacking and punching me until I have black eyes and other injuries; breaking his teacher's finger; and injuring care givers and family members. He attacks others completely unprovoked and has hit strangers in the past.

- 5. I wear a helmet in my home to protect me from G.T.'s blows to my head when G.T. is at home. When G.T. is at home, he will often attack me in my sleep or wake me up in the middle of the night and demand that I cook for him. If I refuse, he will hit me and cause injury.
- 6. G.T.'s treatment prior to his admission to JRC included: behavior management strategies, 1:1 staffing, crisis management paraprofessionals, transportation paraprofessionals, speech services, and a wide variety of other behavioral interventions, as well as the prescription of psychotropic drugs including Klonopin, Clonidine, and Abilify, all of which can have serious side effects. G.T.'s teachers have reported that he is frequently tired as a result of his medications.
- 7. G.T.'s placement history includes public school placement in New York, including Early Intervention, Preschool special education services, and special education services at P.S. #176 and M.S. #181, where he was in the autistic programs and he required a transportation paraprofessional and a 1:1 crisis management paraprofessional. In 2007, G.T. was hospitalized at Mt. Sinai Hospital after an extremely explosive aggressive episode, and prescribed Klonopin, Clonidin, and Abilify.
- 8. G.T. was also treated for approximately ten years by at the Albert Einstein College of Medicine's Rose F. Kennedy Center in the Bronx, and prescribed a protective helmet to address his constant head banging, which he refused to wear. His physician at the Kennedy Center, a pediatric specialist in neurodevelopment disabilities, Rosa M. Seijo, M.D., noted that the psychotropic medications prescribed for G.T. at Mt. Sinai in an attempt to control his

behaviors were not effective. Dr. Seijo stated that a 24 hour residential placement was strongly recommended and necessary. See Letter of Rosa Seijo, M.D., dated September 13, 2007, attached hereto at Exhibit 1.

- 9. Prior treatments were not successful in treating G.T.'s behaviors, and such behaviors have prevented him from making academic progress.
- 10. G.T.'s prior placements and treatment did not meet his needs. While G.T. was admitted to Mt. Sinai, he underwent a psychiatric evaluation. The psychiatrist recommended a 24 hour residential setting and ABA behavioral 1:1 training at home until such a placement was found.
- 11. I visited several residential schools, including the Anderson School in New York, Red Hook in New York, and Devereux in New Jersey. All of the schools rejected G.T. after receiving his referral packet.
- 12. G.T. was admitted to JRC on February 29, 2008 and JRC was placed on G.T.'s Individualized Education Program ("IEP").
- 13. Since his admission to JRC, G.T. has been on a positive-only behavior modification treatment plan. G.T. is no longer on any antipsychotic medications. JRC has employed multiple mechanisms to keep G.T. safe including: providing 1:1 staffing for 8 hours per day, a special classroom equipped with safety mats, a karate helmet to protect against injury from head-banging, supervision in a residence with increased staffing levels and enhanced safety precautions, and emergency restraint when necessary. Despite these protections, G.T. still exhibits severe problematic behaviors and has been unable to make any visits home or participate in any field trips.

- 14. Since his admission to JRC, G.T. has engaged in severe head-banging, to the point where he has made holes in the walls of his classroom and residence. G.T's head-banging behavior has recently been so severe that he suffered a stroke as a result and was hospitalized. His head banging has left him with a permanent limp on his right side. Following his hospitalization, one of his consulting physicians stated that if G.T.'s head banging continues, it is likely to kill him. See letter from Robert K. Rosenthal, M.D., dated August 12, 2009, a copy of which is attached hereto at Exhibit 2 (stating that G.T.'s head banging "going forward in all probability will cause a fatal hemorrhage").
- 15. In addition to engaging in life-threatening head banging, G.T. also punches the walls with his fists, has destroyed property such as computers and shelves, and has exhibited severe unprovoked aggression against staff on multiple occasions. He continues to engage in screaming, yelling, foot stomping, masturbating, touching his genitals through his clothing, and disrobing at inappropriate times and in inappropriate places. G.T. also refuses to follow staff directions, refuses physical prompting, and refuses to be cooperative with staff.
- 16. G.T.'s severe problematic behaviors interfere with his ability to make meaningful academic progress.
- 17. G.T.'s clinician at JRC has informed me that in his opinion the least restrictive and most effective treatment for G.T. would be a behavior modification treatment plan with the addition of aversive interventions, including the Graduated Electronic Decelerator ("GED") device, to treat his aggressive, destructive, major disruptive, health dangerous, and noncompliant behaviors, including the severe and life threatening head-banging which he engages in. I have been informed about the nature of the aversive interventions and their proposed use with my child and have provided JRC with my written consent to add aversive interventions to his

treatment plan to address his severe problematic behavior. Additionally, before treating G.T. with aversive interventions, JRC will seek the approval of a Human Rights Committee, a Peer Review Committee, G.T.'s school district and, a Massachusetts Probate Court judge. In addition, G.T. will be represented by a court-appointed attorney to protect his interests in the Probate Court proceeding.

- 18. I have been informed, by G.T.'s clinician at JRC, that under the regulations of the New York State Education Department, 8 N.Y.C.R.R. §200.1 *et seq.* ("NYSED Regulations"), my child cannot have access to this potentially life-saving treatment, even though: (1) I have consented to it; (2) it is recommended by G.T.'s treating clinician at JRC; and, (3) G.T. has been physically examined by a physician, who has found no medical reason why G.T. should not receive this treatment. I have also been informed that the NYSED Regulations reduce the effectiveness of aversive interventions by restricting their use in a manner not supported by the professional literature. The NYSED Regulations also require submission of the proposed treatment plan to an unqualified panel who will never examine G.T., will never speak to me about G.T., and will only do a paper review of G.T.'s treatment needs. In addition, the NYSED Regulations impose a ban on the use of aversive interventions after June 30, 2009 which means aversive interventions cannot be added to G.T.'s IEP and treatment plan. I do not want G.T.'s treatment at JRC to be subject to the NYSED Regulations.
- 19. I believe that JRC's behavior modification treatment program, including aversive interventions such as the GED to address his aggressive, destructive, major disruptive, health dangerous, and noncompliant behaviors, is necessary to treat G.T.'s severe problematic behaviors, and is his only chance to receive an education and make social and behavioral progress, as well as to develop a rewarding relationship with his family. No other treatment has

been successful at providing G.T. with the opportunity to make meaningful academic and social progress and contribute to his community and G.T. should not be deprived of the opportunity to have this treatment. No other school can provide G.T. with the opportunity to make more progress than he is making at JRC, and no other school will accept my son. The addition of aversive interventions to his program at JRC will help G.T. to make meaningful behavioral and educational progress.

20. G.T. is currently at risk of further physical harm. If his behaviors are not treated properly, they could result in permanent physical disfigurement, massive pharmacological intervention and associated side effects, frequent physical and mechanical restraint, severe injury to others, incarceration, institutionalization, or even death. G.T. needs aversive interventions to protect him against this physical harm and provide him access to a program and services within which he can make meaningful behavioral and educational progress.

	I DECLARE	UNDER I	PENALTY	OF P	ERJURY	THAT	THE F	OREGO]	ING IS	TRUE
AND	ACCURATE.									

Executed on: December 2, 2009

s/ Carmen Pena Carmen Pena

## **EXHIBIT 1**

JAN-17-2008 11:22 FROM: REGION 6 CSE

7187587640

TO: 7818216020

P.21/42

September 13, 2007

To whom it may concern:

I am Dr. Seijo a board certified developmental/behavioral pediatrician writing on behalf of one of my clients Grand Research Retardation and severe behavioral issues which have become significantly worse over the last year. He is currently on Klonipin, Clonidine and Abilify in attempts to control his behaviors without a great response. He was recently hospitalized at Mt. Sinai for aggression and explosive outbursts. He has recently become a danger to his family with his aggressive outbursts especially towards his mother. I strongly recommend a 24 hour residential setting with specialized trained staff with expertise with children with severe behavioral and developmental issues. The necessity for the 24 hour placement is due to his increasingly disruptive externalizing behaviors which is making daily care of him by his mother impossible as well as his attendance in any kind of educational center that does not provide 24 hour interventions.

Sincerely,

Rosa Scijo, M.D.

Developmental/Behavioral Pediatrician License #

## **EXHIBIT 2**

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Children's Hospital Boston

300 Longwood Avenue, Boston, MA 02115

Telephone (617) 355-6000

ORTHOPAEDICS/LEXINGTON

(781) 672-2100

To:

Edward Sassaman, MD 240 Turnpike Street Canton, MA 02021

Date: August 12, 2009

Last Name: Patient DOB:

Patient DOB:
Date of Service: 72009

First Name: G

MR#:

Sex: M Tel#:

Dear Dr. Sassaman:

This special needs child was seen today in consultation by me. I did prior to seeing him have the opportunity to review his electronic record the day before he came and I realized then it was complicated and also then in addition reviewed with his 2 mental health assistants who accompany him from the Judge Rotenberg Center in Canton, MA. His and Rotenberg Center in Canton, MA. His the child who is 15 years of age has a habit of banging his head through the wall to the extent that he has injured himself is of definite concern. Thus I did review the note from July 28, 2009 from Dr. David coulter who has a long experience in children with these neurologic problems to the extent that he was evaluated and also that a detailed MRI of his brain was done as well as including details of his vascular supply as well.

With the increase in the head trauma there has been a change in his gait to the extent that he is known to have a right spastic hemiparesis, but more recently he has been limping more and up on his toes more on the right side with a definite right equinovarus foot deformity which possibly is progressive but this information would not come up on the MRI of his brain. The child in addition to the right hemiparesis is listed as being autistic, is nonverbal but he does sit and when you address him he will sort of grunt to acknowledge that he understood as best he can. Lot of details of early history are unknown. In Dr. Coulter's note he notes that the child was there with his mother and there was some question about some urinary dribbling.

The child's MRI was reviewed by me and shows that there is bilateral shrinkage of his brain and I did review the report that pointed out that was no evidence of any hydrocephalus. There was no evidence of any thromboses and the impression was a normal MRI of the brain but it is

D. Barow RN

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The child does have a right spastic hemiparesis right leg more than the arm, so therefore there is some asymmetry inconsistency in that diagnosis because there is more involvement in leg.

Also his foot is in equinovarus deformity and on the x-rays there is more hypertrophy of the fourth and fifth rays so that this in some ways is longstanding because of recent trauma it is possible that he is walking more up on his toes than usual.

I did review x-rays of his hips from July 28, 2009 and his femur on July 21, 2009 all negative. No evidence of any fractures.

His right arm is held with a little increased tone, a little flexion of the elbow. His wrist is in neutral and a little tendency towards intrinsic positive of his fingers.

He stands right tilted up. The pelvis is tilted up but on forward bending with the scoliometer 0-0; he really is fairly straight when he bends forward, bends his knees, levels his pelvis.

The right side demonstrates mild contracture of his right knee, a definite equinovarus deformity of his right ankle, dorsiflexion minus 15 degrees and increased reflexes patella 3+, ankle 2+. Babinski up on the right-side and he has clonus on the right leg as well.

Thus the child does have a number of issues going on. No evidence of any fracture. An intermediate standing deformity of his right foot as evidenced by hypertrophy of the right ray and I did suggest the following recommendations after reviewing all.

Plan would be immediately to go to have an update at the Brockton Hospital where he has a PT appointment already set up. They could see him sooner and I did suggest perhaps they could put a crutch in his left hand which would help stabilize him a bit. I think that is all that is appropriate at this time and see whether they can help his gait and see whether he would do less banging of his head which going forward in all helmet for him if he would wear it, but I doubt he would. Follow up to the attendants in two months was suggested if you think it is appropriate. I did make out a form for them and I will suggest a copy go to the center as well.

Sincerely,

Robert K Rosenthal, MD Past President, American Academy for Cerebral Palsy and Developmental Medicine

CC: Edward A Sassaman, MD 240 Turnpike Street

Canton, MA 02021

Electronically signed by Robert Rosenthal, MD.

U. Baron RN